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Hospital Discharge Plan in Family Caregivers of Children with Coronary Artery Aneurysm in Kawasaki Disease: A Review

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Abstract: Objective: The study reviews status, main time nodes and hospital discharge services for family caregivers of children with Kawasaki disease complicated by coronary artery aneurysm to provide references for the development of hospital discharge preparation services for medical personnel and patients. Background: CAL of Kawasaki disease is the main cause of acquired heart disease in children, but there is not enough research on the readiness for hospital discharge. Design: Systematic review of observational and interventional studies.

Keywords: Hospital discharge plan; Family caregivers; Kawasaki disease; Systematic review

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1. Background

Kawasaki disease (KD) is an acute febrile systemic vasculitis with unclear etiology and mechanism of action. Coronary artery lesions (CAL) are the serious complications of Kawasaki Disease, including coronary artery dilation and coronary artery aneurysm (CAA), which CAA is the most severe and lethal complication of KD [1,2]. In recent years, epidemiological surveys across various regions in China indicate a rising trend in the incidence of Kawasaki disease combined with CAA [3-6]. Furthermore, the prevalence of medium and large coronary aneurysms among children with Kawasaki disease stands at 5.1% [7]. The main treatment for children with CAA during the recovery period includes drug therapy and selective coronary artery bypass surgery [8,9]. Standardized and scientific drug therapy is a prerequisite for selective coronary artery bypass surgery. However, due to the cognitive and self-management abilities of pediatric patients, good readiness of family caregivers for discharge is an important indicator of the compliance and safety of home-based treatment for pediatric patients and is a problem that needs to be addressed in clinical nursing practice [10]. This study mainly reviews the current status, time nodes and key tasks of discharge preparation for family caregivers of children with Kawasaki disease complicated with CAA. The aim is to provide references for improving caregivers' ability and psychological preparation level, ensuring the safety, recovery and improvement of the prognosis of children after discharge.

2. Overview of discharge readiness of family caregivers

2.1. Concept of discharge readiness for family caregivers

Fenwick AM (1979) defined discharge readiness as a judgment of whether a patient receiving inpatient treatment is physically, psychologically and socially prepared for discharge [11]. Due to the special nature of pediatric patients, the recovery of their illness after discharge is mainly the responsibility of their family caregivers. Therefore, the Canadian Academy of Pediatrics proposes that the readiness of family caregivers for discharge refers to the degree of mastery of the relevant knowledge and skills of caring for the child by the primary caregiver at the time of discharge, as well as the level of confidence in caring for the child, including both caregiving ability and psychological preparation [12]. The United States, the United Kingdom, and other Western countries have established relevant documents on discharge preparation services, clarifying the key tasks involved in the evaluation, verification, referral and follow-up of discharge plans. China's research and development on discharge preparation services is relatively late and is still in the initial exploration stage [13,14].

3. Main contents of discharge readiness for family caregivers of children with Kawasaki disease complicated with coronary artery aneurysm

3.1. Drug therapy

Children with CAA require long-term oral administration of anticoagulants such as warfarin and aspirin to prevent coronary artery thrombosis and reduce the risk of coronary artery stenosis, myocardial ischemia, infarction and even sudden death caused by thrombosis [15]. In family environment, common pediatric medication errors include medication configuration errors, medication leakage, excessive or insufficient use, self-discontinuation of medication [16]. There are the following issues regarding standardized medication:

- (1) Difficulty in taking medication. Currently, the dosage forms of anticoagulant drugs used in children are oral tablets, which are not soluble and difficult to convert into liquid form for oral administration to infants and young children. Although direct oral anticoagulants are currently available, this type of oral anticoagulant is only used in adults and has not yet been routinely used in children [17]. Due to the small dosage of warfarin sodium tablets for children and the need for regular adjustments based on the severity of the condition and the child's growth and development level, caregivers have divided the existing tablet drugs, resulting in deviations in the daily dose of warfarin for the child [18]. The monitoring of the effect of warfarin depends on INR measurement and its accuracy directly affects the rationality and effectiveness of drug dosage adjustment.
- (2) Preventing adverse drug reactions. Due to the influence of genetic polymorphism, food factors and drug factors, the efficacy and adverse reactions of warfarin also vary among individuals [8]. Using the INR 2.0–3.0 target range and adjusting the dose based on the severity of CAA can improve the effectiveness of warfarin treatment. At the same time, genetic testing should be used as appropriate to guide the use of warfarin, bone density monitoring and immunization should be carried out, measures to avoid bleeding risks should be implemented and post-bleeding treatment measures should be in place to increase the safety of warfarin treatment for children with Kawasaki disease. Some children are also treated with aspirin, which is safer than warfarin, but there is also a risk of bleeding, such as black stools, skin bruising, nosebleeds, and gastrointestinal adverse reactions such as nausea and vomiting.
- (3) The transition from hospital to home for patients is a high-risk period for medication errors ^[19]. Therefore, during the transition period, it is important to pay attention to follow-up with the families of the affected children, and the families should also maintain active communication with healthcare

workers to ensure medication safety.

3.2. Preparation for surgery

With the continuous progress of medicine, coronary artery bypass grafting (CABG) has become the preferred surgical treatment for children with Kawasaki disease complicated by coronary artery disease. More and more researchers in countries and regions are conducting CABG in such children, and the prognosis of the patients has significantly improved [20-22]. Related studies have shown that most children with Kawasaki disease have varying degrees of improvement in left ventricular function after CABG surgery, without obvious clinical symptoms such as angina, and their heart function is maintained at NYHA class I-II [22,23]. Around 80% of children have unrestricted daily activities, and a small number can even participate in vigorous physical exercise. In addition, female patients who underwent CABG delivered successfully during the follow-up period. Although CABG is currently the preferred surgical treatment, the age of the patient and the presence of complications such as myocardial infarction are prerequisites for whether the patient can accept CABG and expect to achieve a good postoperative prognosis. Research has shown that age is an important factor affecting the acceptance of CABG in children with Kawasaki disease complicated by CAA. In principle, younger children should be closely followed up under regular anticoagulant therapy to delay the surgical age in the surgical plan and increase surgical safety [9].

Besides, the "Diagnosis and Treatment Guidelines for Kawasaki Disease" released by the Japanese Cardiovascular Association in 2020 mentioned that preoperative myocardial infarction is an important factor affecting prognosis. The interval between the onset of Kawasaki disease and the implementation of CABG varies greatly, ranging from as short as one month to as long as several years [22]. Therefore, during the treatment period from home care after discharge to CABG surgery, it is necessary to avoid adverse events such as myocardial infarction, thrombus detachment and cardiogenic syncope in children, ensuring that they can receive CABG treatment at an appropriate and safe age and improve their prognosis.

3.3. Activity management

The literature from adult coronary artery disease research has shown that regular physical activity plays a key role in preventing the development of coronary artery disease by reducing endothelial dysfunction and inflammation ^[24]. To avoid the risk of cardiovascular accidents or even sudden cardiac death during exercise in children with Kawasaki disease, personalized and specific exercise recommendations should be given to all Kawasaki disease patients. Sports activities are a combination of static and dynamic movements. Increasing static movement requires a higher maximum percentage of voluntary contraction, while increasing dynamic movement requires a higher oxygen consumption. For children with Kawasaki disease complicated with CAA, physical activity and sports management should be carried out according to the risk of coronary artery disease. When providing exercise guidance, it is necessary to consider the four factors of exercise frequency, intensity, time and type based on medical history, physical examination and necessary auxiliary examinations. Safety and beneficial individualized guidance should be provided to children from both static and dynamic exercises. Children taking anticoagulants should also be informed to avoid collisional exercises to ensure the best, safest physical condition ^[25].

3.4. Cardiovascular system symptom recognition

Children with Kawasaki disease and associated CAA face a high risk of cardiovascular complications. They may exhibit symptoms from both the cardiovascular and digestive systems. Symptoms of the cardiovascular

system include chest pain, breathing difficulties, excessive crying, pallor, fainting, convulsions and cardiac arrest, while digestive symptoms may include abdominal pain and vomiting [26–28]. Even in the absence of coronary artery enlargement or aneurysm formation, incomplete Kawasaki disease can lead to acute myocardial infarction, posing life-threatening risks to the child [28]. As infants and young children are unable to articulate symptoms, excessive crying, pallor and vomiting frequently mark the onset of acute myocardial infarction in this population [29]. During discharge preparation services, caregivers must be trained to recognize symptoms, as early detection of myocardial ischemia can facilitate prompt emergency care and reduce mortality risks.

4. Discharge preparation services for family caregivers of children with Kawasaki disease complicated with CAA

Chinese scholars Wang H *et al.* (2020) have summarized the best evidence of discharge plan practice, clarifying the key time points for patients to receive discharge preparation services during hospitalization: including the patient's admission 24 hours, hospitalization period, 24 hours before discharge, discharge day, and follow-up after discharge [13]. Based on the key tasks of each time node and the disease characteristics of children with Kawasaki disease complicated with CAA, the time nodes and tasks for the discharge preparation service of family caregivers are as follows.

4.1. On the day of admission

Children diagnosed with Kawasaki disease for the first time, with or without coronary artery disease, have higher demands for symptom observation, treatment and related information from their family caregivers and often experience negative emotions such as anxiety [30,31]. Research shows that in the early stages of admission, caregivers of children with Kawasaki disease have a high level of disease uncertainty, leading to a vague understanding of the disease and treatment concepts of Kawasaki disease [32]. Disease uncertainty is a barrier to discharge readiness, which is not conducive to the recovery of children during hospitalization and home care after discharge [33]. Therefore, on the day of admission, the focus of discharge preparation services should be on:

- (1) Providing relevant knowledge on Kawasaki disease, coronary artery aneurysm, treatment methods, etc. to the child's primary family caregivers;
- (2) From the day of admission, interviews will be conducted to understand and evaluate the discharge preparation needs of the patient's family to identify discharge barriers as early as possible.

4.2. During hospitalization

The discharge plan implementation at this stage mainly involves continuous evaluation, implementation and review of the feasibility of the discharge plan while updating the discharge preparation services based on changes in the condition, treatment and nursing characteristics. Children with Kawasaki disease combined with CAA need to pay close attention to their cardiovascular ischemia symptoms during hospitalization and after discharge. Early identification of the manifestations of myocardial hypoperfusion in children is beneficial for early prevention of myocardial infarction.

In addition, in terms of drug therapy, during hospitalization, the child receives routine treatment with immunoglobulin combined with anticoagulants such as aspirin [34]. Caregivers must be informed to follow the doctor's instructions and take anticoagulants in a standardized manner. Regarding the observation and management of adverse reactions to drug therapy, relevant training needs to be provided to caregivers, including identifying the manifestations of adverse drug reactions and prevention and handling of adverse drug reactions.

Therefore, the focus of discharge preparation services at this stage is to:

- (1) Continue to evaluate the level of discharge preparation needs of caregivers for pediatric patients and develop personalized discharge preparation service plans by using the Caregiver Care Ability Scale to assess the caregiving ability of family caregivers and develop personalized education plans based on the assessment results. After conducting health education, adopt feedback methods to ensure caregivers can master corresponding caregiving knowledge and skills.
- (2) Teach caregivers to assess the child's breathing, body temperature, skin condition and mental state besides developing emergency response plans for chest pain, early prevention and identification of myocardial infarction [35];
- (3) Improving caregivers' medication use literacy by providing risk training on the use of warfarin, aspirin, clopidogrel and other medications to family members and children, including why anticoagulants should be used, how to judge the efficacy of anticoagulants, when to detect INR, which foods and medications can affect INR, adverse reactions and bleeding characteristics, how to avoid or prevent bleeding during the use of anticoagulants, and how to effectively and reliably stop bleeding during bleeding. It is also important to timely track the occurrence of bleeding in pediatric patients, and promptly handle, correct, and retrain any adverse conditions that arise during the treatment process [36,37];
- (4) Provide psychological care to the caregiver. Caregivers of sick children have varying degrees of physical, psychological, social and economic burdens during the care process, which can easily lead to physical and mental problems, affecting their own health status and quality of life, as well as their disease recovery. Therefore, targeted psychological care should be implemented based on the caregivers' characteristics [38].

4.3. 24 hours before discharge

Verify all key issues and discharge preparations during hospitalization to ensure that services provided to patients on or after discharge are not delayed. Develop a verification content form, including drug dosage, duration of use and regular review of INR indicators involving discharge information, family preparation, transportation environment preparation, etc. Confirm that the caregiver will use a mobile phone and collect effective contact information after discharge [39,40].

4.4. On the day of discharge

Evaluate whether the patient meets the discharge criteria and implement targeted nursing measures for patients discharged and referred to external institutions, including providing written referral information forms and health education forms [41,42].

4.5. After discharge

The key task during this period is to follow up and continuously track the effectiveness of the discharge plan. The research results of Orbay I *et al.* (2022) show that the actual problems that patients have after discharge are usually more than the care problems expected by caregivers before discharge and the problems considered by nursing staff ^[43]. According to the diagnosis and treatment guidelines for Kawasaki disease, it is recommended to conduct lifelong follow-ups for children with Kawasaki disease complicated by CAA ^[44,45]. The focus of discharge preparation services at this stage is summarized as follows:

(1) Providing continuity of care: Dynamically evaluating the effect of warfarin on thrombosis in children with Kawasaki disease complicated with CAA, effectively treating coronary artery thrombosis while

- minimizing adverse reactions of warfarin, and preventing the formation of new thrombosis [8,36,46].
- (2) Arrange regular outpatient follow-up, improve coronary angiography and other related examinations, evaluate the disease progression of the child and whether oral medication treatment can be changed to coronary artery bypass surgery and strive to obtain the active cooperation of the child and their family.

5. Conclusion

At present, domestic scholars use WeChat groups and official account platforms to carry out health education for caregivers of children with Kawasaki disease and CAA, which effectively reduces the uncertainty of the caregivers and improves the compliance of children with treatment. However, children with Kawasaki disease complicated by CAA have a long course of illness and complex knowledge points. Considering the different understanding abilities of caregivers, it is not easy for parents to accept teaching and indoctrination through WeChat groups during hospitalization. Moreover, the transition stage from hospital to home is a high-risk stage for adverse events such as medication errors. Therefore, caregivers and medical staff must maintain communication and contact from when the child is admitted to the hospital to follow-up after discharge. The key to treating children with Kawasaki disease combined with CAA is to prevent the formation of coronary artery thrombosis, reduce the risk of coronary artery stenosis, myocardial ischemia, infarction and even sudden death caused by thrombosis, promote coronary artery recovery and improve their quality of life. The research on the discharge readiness of family caregivers of children with Kawasaki disease complicated with CAA in China is still in its early exploration stage, and there is insufficient research on the content of discharge readiness services. Good discharge readiness is of great significance in reducing the incidence of adverse events related to coronary artery disease and improving the quality of life of children. Starting from the characteristics of Kawasaki disease complicated with CAA, treatment and nursing key points, this article formulates the discharge preparation services for Kawasaki disease complicated with CAA, which is the research direction for this special group in the future.

Disclosure statement

The authors declare no conflict of interest.

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